TABLE OF CONTENTS

Page Number

EXECUTIVE SUMMARY

The Maternal and Child Health (MCH) Advisory Board (Board) is pleased to present its Biennium Report 2004/2005 and 2006/2007 Recommendations. This report focuses on the Board's activities during 2004 and part of 2005 along with four priorities for 2006/2007, which they feel are critical to improving the health status of women, infants, and children and the families who care for them residing in Nevada. These priorities are a continuation from those of the current Biennium as the Board feels, while much as been done, much remains to be accomplished. In this report, the Board also presents its perspective on the effect of a changing health care system on access to care for Nevada's families and the findings of the Nevada Year 2000 Five-Year Maternal and Child Health Needs Assessment. In this report, the four priorities have been placed within and address implementation of initiatives that address the priorities established by the Needs Assessment. The Board is committed to ensuring that discussions and decisions on resources are focused on reducing risk factors that lead to poor outcomes in children and their families.

The mission of the MCH Advisory Board continues to be to improve the health of Nevada's children and their families. It is in this context that the Board presents the following priorities:

Priority: Access to comprehensive preconceptual, prenatal and postpartum services for all Nevada women of childbearing age and a medical home for all Nevada children.

Priority: Access to comprehensive Oral Health care for Nevada's families

Priority: Access to mental health services for Nevada's families

Priority: Implementing the recommendations contained in the recommendations and reports of the Fetal Alcohol Syndrome and Perinatal Substance Abuse Prevention Subcommittees (Appendix C and Appendix D) including assurance that all pregnant women in diagnosed substance abusing cases will have a potential treatment option immediately available.

There are many issues to be addressed to accomplish these priorities including:

- the continuing loss of obstetric providers in the state, leading to adverse birth outcomes
- the continued need for access to mental health services for children and their families in spite of great gains in the current biennium
- the impact of Medicaid and Nevada √ Check Up on access including dental access.

INTRODUCTION

This biennial report is organized by the priorities identified by the Nevada Five-Year Maternal and Child Health Needs Assessment for 2000-2005, published July 2000. Methods selected to accomplish the Needs Assessment were used to promote collaboration between state agencies, health entities, community based organizations, parents, youth groups, and the community at large. The extensive efforts to assess the needs of Nevada's MCH populations (which include women, infants and children and the families who care for them) included work and focus groups, public hearings, and data collection and surveys. The Board's four priorities for 2006/2007 complement and are placed within the priorities determined through the Needs Assessment process. A new Nevada MCH Needs Assessment will be completed by July 15, 2005 using the same process; it is not anticipated that the priorities will change significantly.

The Board recommends the State Health Division Administrator urge the Governor and Nevada State Legislature to build on the accomplishments of the 2003 Legislative Session. A strong public commitment to improve the health of Nevada's children and their families, including children with special health care needs, should continue, making addressing the findings of the MCH Needs Assessment a priority for the State. A complete listing of the Needs Assessment priorities may be found in Appendix A.

The Maternal and Child Health Population in Nevada

Nevada's maternal and child health population includes all women of childbearing age, infants, and children, including children with special health care needs. The MCH population represents the most vulnerable population in Nevada. Pregnancy and the formative years of childhood are associated with increased risk of suffering the long term damaging effects of dysfunction, disease, and disability that extend into old age. Conversely, this population also offers the greatest potential for success, with healthy growth and development, and opportunity for a healthy future. The MCH population faces many challenges in today's world that present pressing problems and create unique needs as well as great opportunities to intervene. Prevention including health education, and age and culturally appropriate medical, oral/dental, and mental health services for the MCH population, all essential if Nevada's children are to have a healthy future.

HISTORY OF THE BOARD

Governor Bob Miller first established the MCH Advisory Board through an Executive Order in December 1989. This original Board was formed as a 24-member body to provide the Governor with critical information and recommendations for the planning and provision of health services for women, infants, children, and their families.

In 1991, the Nevada State Legislature passed Assembly Bill 327 (NRS 442.133) to establish the current Board as an 11-member body: nine members to be appointed by the Governor, one member of the Senate, and one member of the Assembly. A listing of current members may be found in Appendix B.

Purpose of the Board

Chapter 442, Section 4 of the Nevada Revised Statutes states: "The purpose of the advisory board is to advise the administrator of the health division concerning perinatal care to enhance the survivability and health of infants and mothers, and concerning initiatives to improve the health of pre-school children, to achieve the following objectives:

1. Ensuring the availability and accessibility of primary care health services;

2. Reducing the rate of infant mortality;

3. Reducing the incidence of preventable diseases and handicapping conditions among children;

4. Identifying the most effective methods of preventing fetal alcohol syndrome and collecting information relating to the incidence of fetal alcohol syndrome in this state;

5. Preventing the consumption of alcohol by women during pregnancy;

6. Reducing the need for inpatient and long-term care services;

7. Increasing the number of children who are appropriately immunized against disease;

8. Increasing the number of children from low-income families who are receiving assessments of their health;

9. Ensuring that services to follow-up assessments are available, accessible and affordable to children identified as in need of those services; and

10. Assisting the Health Division in developing a program of public education that is required pursuant to NRS 442.385, including, without limitation, preparing and obtaining information relating to fetal alcohol syndrome;

11. Assisting the University of Nevada School of Medicine in reviewing, amending and distributing guidelines it is required to develop pursuant to NRS 442.390; and

12. Promoting the health of infants and mothers by ensuring the availability and accessibility of affordable perinatal services."

Following is a brief summary of information comparing Nevada's current MCH health status with the nation's health objectives for the Year 2010 (Healthy People 2010).

SUMMARY OF NEVADA'S MCH HEALTH STATUS AND OBJECTIVES TO BE MET BY THE YEAR 2010

Healthy People (HP) 2010 Objective	Nevada's Current Status
HP 16.1c. By the year 2010, the overall infant mortality rate (deaths of infants under one year of age) in Nevada will be reduced to no more than 4.5 per 1,000 live births	• 2001: 5.7 per 1,000 (Hispanic 5.1) • 2002: 5.65 per 1,000 (Hispanic 3.49) • 2003: 5.62 per 1,000 (Hispanic 4.38)
HP 16.1c. By the year 2010, the infant mortality rate among African Americans will be no more than 4.5 per 1,000 live births.	African American • 2001: 16.5 per 1,000 • 2002: 16.3 per 1,000 • 2003: 11.95 per 1,000
HP 16.10a. By the year 2010, the low birthweight incidence in Nevada will be no more than 5 per 1,000 live births.	• 2001: 7.6% • 2002: 7.51% • 2003: 8.05%
HP 16.10a. By the year 2010, the low birthweight incidence among African Americans will be no more than 5 per 1,000 live births.	• 2001: 12.8% • 2002: 14.75% • 2003: 13.7%
HP 16.6. By the year 2010, the proportion of all pregnant women, regardless of race, who receive early and adequate prenatal care will be increased to at least 90%.	• 2001: 75.5% • 2002: 76.4% • 2003: 79.8%
NV HP 9.7 By the year 2010, births among adolescents aged 15 - 17 will be reduced to no more than 25 per 1,000.	• 2001: 29.15 per 1,000 • 2002: 27.1 per 1,000 • 2003: 27.48 per 1,000
NV HP 9.7. By the year 2010, births among Hispanic adolescents (ages 15 –17) will be reduced to no more than 25 per 1,000.	• 2001: 51.15 per 1,000 • 2002: 50.76 per 1,000 • 2003: 53.64 per 1,000
HP 21.9. Increase the proportion of the U.S. population served by community water systems with optimally fluoridated water to 75%.	• 2001: 69% • 2002: 69% • 2003: 69%
HP 14.24a. Increase to 80% coverage levels of universally recommended vaccines for children aged 19 to 35 months, who receive the recommended vaccines (4DtaP, 3 polio, 1 MMR, 3 Hib, 3 hep B) (MCH National Performance Measure 5)	• 2001: 66 % • 2002: 74.4% • 2003: 74.4% (projected)

2004/2005 Recommendations and Accomplishments

Priority: Access to comprehensive preconceptual, prenatal and postpartum services for all Nevada women of childbearing age and a medical home for all Nevada children and their families.

The Board is pleased to report that effective July 1, 2004, the Medicaid asset test was dropped as recommended in its last report. The Welfare Division implemented it; the Division of Health Care Financing and Policy (DHCFP) is monitoring the change to see if it has any effect on women getting earlier into prenatal care. DHCFP is seeking to see if they are individuals who would have gotten on to Medicaid anyway, that is if they would have been determined eligible while the asset test was in effect except that it would have taken longer for eligibility to be determined. The Board asked for data to see if this action can be linked to better birth outcomes. It is watching this opportunity very closely.

The Birth Defects Registry is being re-activated. Newborn Screening fees were increased as the 2003 Legislature directed to fund it. An FTE was hired in December to begin again the extraction of data from hospital records. Collection will begin in Calendar Year 2005.

Newborn Intensive Care Regulations (NAC 442.411 *et seq.*) were studied by a Subcommittee of the MCHAB and revised to bring them up to current standards. The Subcommittee was comprised of members of the Board and representatives of all the birthing facilities in the state. In a relatively rapid review and analysis that began at the end of January 2004, the revised regulations were revised by the Subcommittee, approved by the Board, and then went to workshop and public hearing and were passed with no comments before the Board of Health on June 25, 2004.

Nevada √ Check Up continues to be fully funded up to the federal allocation.

Newborn Screening was expanded to 31 conditions, placing Nevada at the top among states for the number screened and meeting all current recommendations. (A listing of the disorders screened for may be found in Appendix C.) This entailed an increase in the newborn screening fee, which was approved at the September 12, 2003 Board of Health meeting.

Priority: MCH populations should have access to quality oral/dental health.

Nevada has been recognized by the Centers for Disease Control and Prevention (CDC) as the top oral health program of all those they fund. The CDC grant has been increased from $319,365 to $450,000 per year. The Bureau's Oral Health program has worked with various agencies across the state to promote access to dental care, and with others to promote oral health. Dental care has become managed care in Las Vegas for Medicaid clients. Medicaid

partnered with the Dental School to develop a system where there is a phone number to call for an appointment, and has established a statewide transportation broker (Logisticare) to ensure clients can get to appointment.

The Oral Health program worked with Health Access Washoe County (HAWC) Community Health Center on an early childhood caries prevention project and with the GBPCA on developing and implementing a network of voluntary dentists in Southern Nevada to provide dental care to uninsured children. Dental sealant programs have now been implemented statewide. Many rural communities have developed oral health consortiums and are working to open up dental clinics in their communities. The Oral Health Program is working with them.

Priority: Access to mental health services for Nevada's families
While the Board has had not specific activity other than occasional discussion around mental health, it is pleased that the 2003 Legislature increased funding for mental health services in the state, enabling more Nevadans to receive mental health services.

Priority: Implement the recommendations contained in the recommendations and reports of the Perinatal Substance Abuse and Fetal Alcohol Syndrome Subcommittees.

The Perinatal Substance Abuse Prevention (PSAP) and Fetal Alcohol Syndrome Subcommittees were combined into one PSAP Subcommittee by action of the 2003 Legislature. The Nevada Children's Trust Fund awarded the PSAP initiative $36,000 for a Fetal Alcohol Spectrum Disorders (FASD) public-education campaign. The campaign will be comprised of advertisements on the sides of buses in the Reno/Sparks and in Las Vegas. The campaign will also include advertisements in bus booklets in the Reno/Sparks area. The graphics for the campaign have been supplied by the March of Dimes.

The campaign also includes distribution of FASD warning placards for posting in drinking establishments. State law requires that drinking establishments post FASD warning placards; the placards to be distributed are provided through a previous March of Dimes grant. The campaign will also now distribute information about the dangers of drinking during pregnancy, information on how to obtain help if one cannot stop drinking, and assurance that obtaining such help will not result in the fetal exposure to alcohol being reported as child abuse.

The Health Fund of Nevada funded a two-year pilot project at the Washoe Pregnancy Center to address smoking and second hand smoke. The project is documenting how many women quit smoking, look at the relapse rate, and investigate ways of prevention. It is headed by Dr. Terrance McGaw, Vice-Chairman of the Board.

2004-2005 FOCUS OF THE MATERNAL AND CHILD HEALTH ADVISORY BOARD

Through 2004 and now 2005, the Board continues its mission to provide comprehensive advice and guidance to the State Health Division (SHD) to ensure the enhancement and development of vital services to promote the healthy birth, growth, and development of Nevada's children and healthy families.

As its top priorities, the Board has again established access to care for comprehensive preconceptual, pregnancy and postpartum services, as well as access to primary care, oral health and mental health services. It also urges the implementation of the recommendations contained in the Reports of the Fetal Alcohol Syndrome and Perinatal Substance Abuse Prevention Subcommittees (discussed on page 7). Through the course of the current biennium the Board heard many presentations and deliberated on the effect of a lack of access to care for pregnant women and children; continuing problems with dental access; and the unmet need for mental health services for families. It continued support for the Perinatal Substance Abuse Prevention Subcommittee, ensuring continued attention in particular on the prevention of fetal alcohol syndrome and smoking during pregnancy, and access to treatment for pregnant women diagnosed as substance abusing.

In addition to concerns about access to preconceptual, pregnancy and postpartum care, primary care, dental, and mental health care, the Board continues to monitor change in access to specialty services needed by children with special health care needs (CSHCN) including genetic services. It is monitoring and supporting the activities of the Real Choice Systems Change grant, a grant funded by the Centers for Medicare and Medicare to support the development of systems of care for Nevada's CHSCN that are community based, family centered, culturally appropriate and comprehensive.

The Board is very pleased and congratulates the Divisions of Welfare and Health Care Financing and Policy (DHCFP) for dropping the asset test for pregnant women and children effective July 1, 2004. DHCFP is monitoring the effect of this change on birth out comes, which the Board is following very closely.

Study after study has demonstrated that entering a pregnancy healthy, and receiving continuous pregnancy care starting early in the pregnancy along with support following birth are vital to healthy birth outcomes and healthy subsequent births. The Board continues to be concerned about access to care for women who are contemplating pregnancy, are pregnant, or have just given birth. Gains in healthy birth outcomes of the last decade have been lost or been unchanged in the last reporting year. Early entry into prenatal care was 79.8% in 2003, placing Nevada in the lower 20% in the Nation. Infant mortality stayed at 5.6%, in line with prior years. Low birthweight went up to 8.05%, up from 7.5 in 2002. Infant mortality remains at 5.6 per 1,000 births, as it has been for several years; there has been no progress in

reaching the Healthy People 2010 goal of 4.5 per 1,000 births. Whether due to medical malpractice or other unidentified issues, obstetricians are either leaving the state or limiting their practice to gynecology only. In the fall of 2004 the Board heard that the problem of obstetricians leaving the state is starting to affect access to obstetric care in northern Nevada also. 2004 saw the departure of a major obstetric group from southern Nevada. The Board urges long-term action to stop the exodus of obstetric care physicians and assure access to necessary obstetric care for all Nevada women.

Oral health and mental health are two of the top priorities established by the MCH Needs Assessment, and were found to continue to be top priorities in the studies and focus groups held for the Legislature's Rural Health Task Force. The Board has heard many reports on the development of access to dental services for the populations served by Nevada √ Check Up and Medicaid. Improvements in access to dental care have been made in Clark County with the implementation of dental managed care, but much remains to be done, in both the north and in rural Nevada.

Mental health services for Nevada's families are a factor in many of the issues of concern to the Board, including healthy birth outcomes, child development and substance abuse including fetal alcohol syndrome prevention. With funding from CDC and the Association of Maternal and Child Health Programs, a Nevada team was brought together to address collaboration around Teen Pregnancy Prevention (TPP), Sexually Transmitted Diseases (STD) and HIV stakeholders for adolescents, to produce one Action Plan for this population. Preventing HIV, STD and teen pregnancy in adolescents will help prevent mental health issues in this population. This initiative has brought in Mental Health and Substance Abuse, and turned into an action around Risk Reduction. The group is looking to develop a State Adolescent Strategic Health Strategic Plan to collaboratively address issues.

The Primary Care Development Center (PCDC) had a grant from HRSA that supported an interdisciplinary training program for students in the health professions in Elko County. The focus of this grant included mental health. PCDC also worked with the Great Basin Primary Care Association and Nevada Health Centers to craft a "Governor's Letter" that was sent by the Governor to the Shortage Designation Branch of the Bureau of Health Professions and subsequently approved to build a Federally Qualified Health Center in Elko.

Board members continue to serve as mentors to the members of the Governor's Youth Advisory Council. The primary goal of the Council is to improve the health status of youth in Nevada by educating those creating programs and making decisions directly impacting youth. The Council continues to focus primarily on making recommendations regarding reducing the rate of teen pregnancy. The assembly presentation the Council developed, entitled "Abstinence Works", was presented to 583 students during the past school year. The Council has identified teen pregnancy prevention, drug and alcohol use, and suicide as their priorities for the coming biennium.

In summary, comprehensive prevention has been and remains the focus of the Board. This includes the prevention of teen pregnancy, prematurity, and low birthweight babies. It includes preventing substance abuse in pregnant women. It means preventing dental disease and promoting good oral health, and access to primary care, including dental care, and mental health services for all Nevada families, all the components that make up a medical home. The need for an ongoing source of health care, defined as a medical home, for all children, including children with special health care needs, is a priority at the national level[1], and Nevada should be no different. The child without a medical home who is not healthy physically, mentally, and/or has poor oral health cannot grow and develop properly, or be successful in school. Good health can only occur if there is access to good preconceptual and pregnancy care with healthy births for mothers and support after birth, along with primary care, dental care, and mental health medical homes for all children and their families, including children with special health care needs. To have healthy children in healthy families, a continuum of comprehensive, culturally appropriate services is needed statewide.

[1] American Academy of Pediatrics. Policy Statement, Pediatrics Vol. 110. No. 1 July 2002.

RECOMMENDATIONS for 2006 and 2007

The Board is grateful for the continued commitment shown to family health during the 2003 Legislative Session, particularly those that increased access to Medicaid and Nevada √ Check Up. It urges continuation and expansion of this commitment in the upcoming Legislative Session by addressing the priorities identified through the Board's MCH Needs Assessment process:

Nevada MCH Needs Assessment Priorities: Increase healthcare access and address insurance and financial gaps for the MCH populations; increase the amount of outreach and enabling services available for the MCH populations; and address the need for additional medical personnel among the MCH populations.

MCH Board priorities: Access to comprehensive preconceptual, prenatal and postpartum services for all Nevada women of childbearing age and a medical home for all Nevada children and their families.

Access to preconceptual, pregnancy and postpartum care is crucial for healthy birth outcomes and healthy subsequent births. The medical malpractice issue continues to be a major concern at this time. The DHCFP and through them the Board are watching the effect of the dropping of the asset test on Medicaid coverage for pregnant women and children. This is an important step in promoting access to care for the uninsured.

Funding for Baby Your Baby was lost during the current biennium as anticipated. The Board understands that women with high-risk pregnancies need access to an array of services, including perionatologists and other specialty care such as genetics, domestic violence and substance abuse screening, etc. in order to have a healthy birth. All women need to know and take advantage of the benefits of preconceptual folic acid, help with smoking, alcohol and drug abuse cessation, the benefits of planning and spacing pregnancies, resources to help if they are involved in a domestic violence situation, and other services that may be beneficial to one woman but not to another. This becomes critical when they are pregnant, whether they are high-risk medically or not.

To replace Baby Your Baby (BYB), the Health Division developed the MCH Campaign. This multi-faceted campaign similar to BYB was implemented January 1, 2004. It includes a 1-800 outreach phone line (the same number that was BYB's, 1-800-429-2669),and a media campaign. It differs in that funds have been pulled together to create contracts with local agencies that are willing to serve pregnant women who do not have insurance. They are required to provide all the services listed in the above paragraph or have referral resources in place for them. Data is being collected that will tell the story on the success or problems with this approach. The first contract, let after a RFP process, went to University Medical Center in Las Vegas. Additional contracts will be sought in the upcoming

biennium after the Campaign has been through the budget process. In addition to one in the south, these contracts will be one for the North and one in a rural community if possible. The media campaign is targeting those groups most at risk to experience infant mortality and low birth weights. The Board supports these changes to the prenatal outreach program as they are addressing problem areas with birth outcomes directly.

The 1995 MCH Needs Assessment found access to care the primary concern and priority for the MCH populations. The 2000 MCH Needs Assessment found progress has been made on access to care for children with the implementation of Nevada √ Check Up, but it still remains a priority. Preliminary findings with the 2005 MCH Needs Assessment indicate access to care remains a concern. The opportunity supplied by Nevada √ Check Up should be fully realized as it currently is. There are several efforts that can be undertaken to ensure full utilization of Nevada √ Check Up which so far are in place. First, there should be no cap on enrollment and funding, up to the dollar match required to capture the full federal allocation, should be appropriated.

In addition, outreach is a critical component of efforts to maximize the opportunities presented by the Children's Health Insurance Programs; Nevada √ Check Up is no exception. "Without effective outreach to find, enroll, and ensure services for these children, the well-intentioned efforts of CHIP [Children's Health Insurance Program] will fail. Collaborating and making outreach a top priority will help fulfill the promise of CHIP to improve children's health."[2] The Board supports using community-based organizations including Federally Qualified Health Centers (Rural and Community Health Centers included), schools, providers of all types, all available resources for Nevada √ Check Up as well as Medicaid outreach and education. A multifaceted effort designed to enroll low-income children in Nevada √ Check Up or Medicaid should be utilized by the state in its efforts to achieve optimal enrollment and participation. The current initiative funded by Robert Wood Johnson should be supported. Should proposed federal funding to maximize outreach for both Children Health Insurance Programs and Medicaid materialize, it should be fully accessed and used by Nevada to ensure as many children as are eligible are enrolled in these two critical programs for children. Finally, the 2002 Needs Assessment suggests the enrollment forms and eligibility rules for Nevada √ Check Up and Medicaid be reassessed to increase the recruitment and retention of eligible children. This has somewhat occurred with Nevada √ Check Up, whose application is on-line in English and Spanish, (at http://nevadacheckup.state.nv.us/). The Board applauds this effort.

Promoting universal access to prenatal care has been a priority of the Board since its inception. With the potential loss of Baby Your Baby, other innovative, researched ways to get women into early prenatal care need to be explored. Programs and services for women

[2] From *Bright Futures and Managed Care- Outreach to Children: Moving from Enrollment to Ensuring Access.* Paper by Mary Brecht Carpenter, RN, MPH and Laura Kavanagh, MPP, for the National Institute of Health Care Management with funding from the Health Resources and Services Administration

of child-bearing age should be comprehensive, from pre-conception to post-partum care, should maintain and build on successful efforts such as Baby Your Baby, be culturally appropriate and community-based, and include enabling services such as transportation, childcare, and translations. As with Baby Your Baby, new efforts should be based on public-private partnerships. Other solutions can include mandating the inclusion of prenatal care by all third-party payers; taking a close look at the Baby Your Baby evaluation and addressing the reasons women gave for not accessing prenatal care; establishing presumptive Medicaid eligibility for pregnant women; and continuing to address the populations most at risk for domestic violence and substance abuse, both of which can prevent a woman from seeking prenatal care. **The Board cannot emphasize enough that early and continuous prenatal care is necessary for all pregnant women in the state to ensure appropriate interventions in at-risk pregnancies and the birth of healthy infants.**

Nevada MCH Needs Assessment Priority: MCH populations should have access to quality oral/dental health.

MCH Board priority: Access to comprehensive Oral Health care for Nevada's families.

This current Biennium has seen much progress in promoting access to dental services and the promotion of oral health for Nevada's citizens. In 2004 an Oral Health Summit was held that brought stakeholders from statewide. A copy of the report from the Summit and its recommendations may be found at http://health2k.state.nv.us/oral/. Reports on the state of oral health in Nevada's 17 counties as well as other reports may also be found there. The Board supports the recommendations of the summit, which include to maintain and expand an Oral Health System in Nevada, to develop policy to promote oral health, to develop sustainability of the State Oral Health Program, to promote effective disease prevention and treatment strategies and programs, to increase access to direct dental services, and to reduce barriers to care.

There are 27 Dental Health Professional Shortage Areas covering most of the state. This is 6 more than the last Board report; these six are all to be found in Las Vegas. To this goal the Board supports the dental residency program at the University of Nevada School of Medicine and the establishment of the dental school in Nevada.

In July 2001, the State Health Division received a grant from the Centers for Disease Control and Prevention (CDC) that enabled the establishment of an Oral Health office in the Division. As reported on page 6, the Oral Health Program is now recognized by CDC as the top program it funds and has the largest oral health grant of all CDC grantees. The Oral Health Program now has staff to promote prevention activities that including a statewide

sealant initiative, training on the prevention of Early Childhood Caries and P.A.N.D.A. (Prevent Abuse and Neglect through Dental Awareness), technical assistance to help facilitate community development of dental services, and fluoridation. A media campaign on good oral health is in process and an oral health curriculum for schools has also been produced. The Oral Health Program has completed surveillance of sealants on third graders in Nevada, and found 32.5% had sealants in 2003. They have also completed surveillance of Head Start programs in the State. There they found a statewide average of 54% of the children with caries experience. When broken down by region, Washoe County Head Start had 64.9 % caries experience, Clark County had 50.3%, and rural had 53.7%. It is possible that the effect of fluoridation, implemented in 2000 in Clark County, is now surfacing.

The Oral Health Office worked very closely with the Great Basin Primary Care Association (GBPCA) to recruit dental providers to underserved communities in Nevada as allowed under SB 133 passed in the 2001 Session. The Board recommended that the provisions of SB 133 not be sunsetted as will happen at the end of the current biennium if it is not extended, or if it does sunset, the Board recommends that Nevada join a regional board examination.

The Oral Health Office continues to provide fluoridation education and support. The Board, as in years past, continues to support the optimum fluoridation of Nevada's water systems as a major prevention activity for oral health.

The Board supports the development of the Oral Health Office and all the progress it has made and hopes that when the CDC funding ends other resources have been identified to keep it operational.

Nevada MCH Needs Assessment Priorities: Increase access to mental health services, providers, facilities, resources, and payor sources for the MCH populations.

MCH Board Priority: Access to mental health services for Nevada's families.

Mental health disorders are as real, common, and treatable in children as they are in adults. The Federal Center for Mental Health Services estimates that as many as 1 in 5 children will experience a diagnosable mental, emotional, or behavioral disorder before the age of 18. One in 10 may actually have a serious emotional disturbance so severe it interrupts the child's ability to function socially, academically, or emotionally. Left untreated, childhood mental disorders can lead to school failure, substance abuse, suicide, and involvement with the juvenile justice system. Nationally, nearly two-thirds of children in need of mental

health treatment services do not receive the care they need, many of them young children[3]. They face a lack of accessible services, insurance plans, HMOs and Medicaid that will not cover adequate treatment or won't cover treatment at all, and the stigma too frequently associated with mental illness. National studies show between 5 % and 7 % of youth use mental health services, as opposed to the approximately 65 percent of youth who could use them (National Survey of America's Families, the Urban Institute). Children with special health care needs have an even more complex need for services with health care needs compounded by mental health needs. Children with fetal alcohol syndrome, for example, have multiple physical and mental disabilities. They need providers who can adequately diagnose and treat them as well as enabling services that support the care taking adult as well as the child. The 2003 Nevada Youth Risk Behavior Survey found that Nevada's suicide rate for youth who attempted suicide one or more times in the last 12 months ranged from 10 % in the 6th grade (up from 9% in 2001) to 12.6 % in the 8th grade (down from 16% in 2001) for the middle school, and from 10.3 % in the 9th grade (down from 11 % in 2001) to 3 % in the 12th grade (down from 5% in 2001) in high school, with a high of 12.6 % in the 8th grade. (The dropout rate is one possible reason for the lower 12th grade rate). The percentage of students who attempted suicide during the past 12 months and had to be treated by a doctor or nurse averaged 33.2 % for high school (this statistic was not collected in the middle school), up from 32 % in 2001.

Mental health services for children are often hard to find, and are fragmented, provided in medical settings, school systems, child welfare offices, and juvenile justice facilities. The Needs Assessment found there is a lack of qualified mental health providers and sufficient mental health resources to work with the CSHCN's conditions. Lack of trained providers and financial resources are a major factor in this problem. There are 15 mental Health Professional Shortage Areas in Nevada; most of Nevada has been designated a Mental Health Professional Shortage Area. The Board supports any initiatives to expand access to mental health services for Nevadans, including the MCH populations.

Although the priorities established by the 2000 MCH Needs Assessment did not specifically address Perinatal Substance Abuse and Fetal Alcohol Syndrome Prevention, the Board is very concerned about the impact of tobacco, drugs and alcohol on Nevada's families and supports its fourth and final priority:

MCH Board Priority: Implementing the recommendations contained in the recommendations and reports of the Perinatal Substance Abuse and Fetal Alcohol Syndrome Subcommittees, including assure that all pregnant women in diagnosed substance abusing cases will have a potential treatment option immediately available:

[3] Howard, K. et al. Patterns of Mental Health Service Utilization. *Archives of General Psychiatry* 53:696-703, 1996, from Healthy People 2010.

The Board's Perinatal Substance Abuse Prevention initiative (PSAP) established in 1995 includes Fetal Alcohol Syndrome Prevention (FASP, formerly a separate Subcommittee as noted on page 7). The Board asks for continued support for this project in the future. Both the PSAP Subcommittee and the Board cannot emphasize enough the need to have a treatment option immediately available when a pregnant woman is diagnosed with a substance abusing problem.

Perinatal substance abuse results in premature, low birthweight and small for gestational age infants, as well as children with Fetal Alcohol Syndrome and other birth defects such as cleft palate/craniofacial conditions which have long-term, even life-long, impacts on all aspects of family and community life. Included in the Board's recommendations are the need to conduct a prevalence study to determine patterns of alcohol, tobacco and other drug (ATOD) use by pregnant women across the state [4]; routine prenatal screening by physicians should include questions about ATOD use; and treatment slots should be increased so that every woman who is diagnosed with a substance abusing program has a treatment option immediately available. A report of the FASP Subcommittee on the "Best Means of Measuring the Frequency of FAS in Nevada" and the "Best Means of Preventing FAS in Nevada," as previously required by NRS 442.355, may be found in Appendix D. In both reports the recommendations are found on pages 6 and 7.

[4] Centers for Disease Control and Prevention: Fact Sheets "Smoking and Pregnancy" and "Smoking Prevalence and Exposure to Tobacco Smoke Among Children", November 7, 1997, Office on Smoking and Health, and Fact Sheet "Tobacco Use", March 1996, Office of Women's Health; and Fact Sheet

CONCLUSION

The Maternal and Child Health Advisory Board endorses the findings of the Nevada Five-Year Maternal and Child Health Needs Assessment 2000-2005, particularly as it relates to supporting and protecting the health status of Nevada's mothers and children, including children with special health care needs. It also endorses the recommendations of its Perinatal Substance Abuse Prevention Subcommittee. Through all its deliberations the Board is committed to promoting wellness for all of Nevada's families, and seeks to ensure that initiatives that address and/or include prevention are not lost in Congressional and State action that may impact services for mothers and children and their families.

The Board will give and urges the Legislature and Governor to give special attention to the four priorities reflected in this document (summarized on page 2). While there has been progress, much remains to be done to improve the health status of Nevada's mothers and children in terms of ensuring access to preventive and primary health care, particularly oral health care and mental health services (a medical home), prenatal care, and prevention and treatment initiatives regarding substance abuse. The Board supports the maintenance and/or creation of safety-net providers and is available for consultation as needed. The Board emphasizes the need for a continuum of statewide services from pre-conception to adulthood that are family-centered, community-based, culturally appropriate[5], comprehensive, and cost effective. Only then can Nevada be assured of a healthy maternal and child population.

[5] Culturally appropriate is defined as "A set of attitudes, skills, behaviors and policies that enable organizations and staff to work effectively in cross-cultural situations. Cultural competence reflects the ability to acquire and use knowledge of the health-related beliefs, attitudes, practices, and communication patterns of clients and their families to improve services, strengthen programs, increase community participation, and close the gaps in health status among diverse population groups." From Cultural Competence Works, Health Resources Services Administration.

APPENDIX A

NEVADA MCH NEEDS ASSESSMENT TEN PRIORITIES:

- MCH populations should have access to quality oral/dental health
- Create a unified data system and surveillance system to monitor services delivered to the MCH populations
- Create "braided" services and "one-stop shopping" for CSHCN resources in Nevada
- Decrease the incidence of domestic violence among women of child-bearing age
- Increase healthcare access and address insurance and financial gaps among the MCH populations
- Increase the amount of health education available for the MCH populations and providers
- Increase the amount of innovative programs that address self-esteem and behavior modification in children 1-9 and adolescents 10-21
- Increase access to mental health services, providers, facilities, resources, and payor sources among the MCH populations
- Increase the amount of outreach and enabling services available for the MCH populations
- Address the need for additional medical personnel for the three MCH populations

APPENDIX B

MATERNAL AND CHILD HEALTH ADVISORY BOARD MEMBERS 2004-2005

Michelle Kling, RN. Reno, NV, representing public health Washoe County

Roger Volker Mdiv. Chairman. Carson City, NV, representing primary care

Maggie Carlton. Las Vegas, NV, representing the Senate

Suzanne Magleby. Las Vegas, NV, representing Clark County Social Services

Genie Ohrenschall. Las Vegas, NV, representing the Assembly

Raquel Knecht, MA. Carson City, NV, representing social services

Donald Kwalick, MD, MPH. Las Vegas, NV, representing public health Clark County

Terrance McGaw, MD. Vice-Chairman. Reno, NV, representing obstetricians and gynecologists

Jeffrey Wrightson, MD. Las Vegas, NV, representing obstetricians and gynecologists

Beverly Neyland, MD. Las Vegas, NV, representing the School of Medicine

Terri Rosenberg. Las Vegas, NV, representing consumers

APPENDIX C

Nevada Newborn Screening Disorders – 31 Total

2 Endocrine
- Congenital Adrenal Hyperplasia
- Congenital hypothyroidism

1 Hemoglobin
- Sickle cell disease and other hemoglobinopathies

2 Metabolic Disorders
- Biotinidase deficiency
- Galactosemia

6 Amino Acid Disorders
- Arginase Deficiency
- Argininosuccinate lyase deficiency (ASA)
- Citrullinemia
- Homocystinuria
- Hyperphenylalanemia, including phenylketonuria
- Tyrosinemia

14 Organic Acid Disorders
- Beta-ketothiolase deficiency
- Glutaric academia, Type I
- Isobutyryl CoA dehydrogenase deficiency
- Isovaleric academia
- Malonic aciduria
- Maple syrup urine disease
- Methylmalonic acidemias (8 types)
- Propionic academia
- 3-Hydroxy-3-methylglutaryl (HMG) CoA lyase deficiency
- 2-Methyl-3-hydroxybutyryl CoA dehydrogenase deficiency
- 2-Methylbutlyryl CoA dehydrogenase deficiency
- 3-Methylcrotonyl CoA carboxylase deficiency
- 3-Methylglutaconyl CoA hydratase deficiency
- Multiple carboxylase deficiency

6 Fatty Acid Oxidation Disorders
- Carnitine uptake/transport defects
- Multiple acyl-CoA dehydrogenase deficiency (MADD)
- Short chain acyl-CoA dehydrogenase deficiency (SCAD)
- Medium chain acyl-CoA dehydrogenase deficiency (MCAD)
- Long chain 3 hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
- Very long chain acyl-CoA dehydrogenase deficiency (VLCAD)

APPENDIX D

Report of the Fetal Alcohol Syndrome Subcommittee to the Maternal and Child Health Advisory Board on 5/14/02: Best Means of Preventing FAS in Nevada

SYNOPSIS: Statute requires that the Fetal Alcohol Syndrome (FAS) Subcommittee of the Maternal and Child Health Advisory Board identify the most effective means of preventing FAS. The statute itself identifies means of preventing FAS in Nevada:

- A FAS-prevention public education campaign;
- Development of curriculum for providers of healthcare and other services;
- Development of screening guidelines to identify pregnant women at risk of drinking during pregnancy and to identify children with FAS;
- Development of materials for training school personnel in screening and referral of children with FAS; and
- Development and promotion of guidelines for preventing alcohol consumption by pregnant women and for their increased use of substance-abuse treatment services.

The most effective means of preventing FAS in Nevada is to attain compliance with these requirements. In the course of doing so, the problem of unplanned pregnancies must also be addressed since alcohol can do its most severe damage during the early stages of pregnancy when a woman may not realize she is pregnant. It also must be recognized that birth outcomes can be enhanced by termination of drinking at any time during pregnancy, and that FAS-prevention efforts must be coordinated with existing activities such as substance abuse treatment and prevention.

Progress has been made towards development of the elements of FAS-prevention required by statute, but full compliance with the statute has not yet been attained. The core element is public education, and truly adequate FAS-prevention public education will require that additional funding sources be obtained. Training materials for school personnel, formal guidelines for screening children for FAS, and formal guidelines for preventing alcohol consumption by pregnant women should be developed by the Subcommittee during 2002.

Six recommendations appear at the end of the report.

NRS 442.350 *et seq* requires that the Fetal Alcohol Syndrome (FAS) Subcommittee of the Maternal and Child Health Advisory Board (MCHAB) "…shall identify the most effective methods of… Preventing fetal alcohol syndrome." NRS 442.350 *et seq* itself identifies effective methods of preventing FAS in Nevada.

1. <u>Develop and implement a FAS prevention public education campaign (NRS 442.385).</u>

Public education is by far the most important of the elements of FAS-prevention required by statute. Public education is generally considered to be the substrate upon which all FAS-prevention efforts rest: Knowledge of the hazards of drinking during pregnancy can reduce the frequency of such drinking, resources to address FAS are of little use and are seldom utilized if they remain unknown to the public, and public education is required to build public support for FAS-prevention efforts.

Approximately 1,600 FAS-warning placards have been sent to drinking establishments registered with the Nevada Division of Taxation. Through grant funding from the March of Dimes, approximately 3,500 more will be mailed during 2002, with focus upon distribution to convenience stores.

Since 1989, alcoholic beverage containers have been required to have the Surgeon General's warning, which includes a warning that drinking alcohol during pregnancy can cause birth defects. This warning is small, easily ignored, and is absent when alcoholic beverages are purchased by the glass.

The FAS warning placards, designed for posting at point-of-purchase or in the women's restroom, are large enough to be read easily, provide a warning in both Spanish and English, and have a photograph of a woman with her child who has FAS, making the placard very difficult to ignore. These placards also have informational tear-offs providing information on how to obtain prenatal care and substance abuse treatment, and providing assurance that a pregnant substance-abusing woman can obtain help in Nevada without being accused of child abuse.

Largely due to funding constraints, FAS-prevention public education at present is not adequate to the task. With an adequate FAS-prevention public education campaign, the great majority of women of childbearing age in Nevada would be aware of the hazards of drinking during pregnancy, would know that substance-abusing pregnant women in Nevada can obtain help without being accused of child abuse, and would be aware of how to obtain birth control services, substance abuse treatment, and prenatal care. It is very unlikely that this is the case at present.

2. Develop model curriculum on FAS with the assistance of the University of Nevada School of Medicine, which meets the continuing education requirements of providers of healthcare and other services.

Curriculum has been developed on the hazards of drinking alcoholic beverages during pregnancy, on screening pregnant women for alcohol abuse, and on providing pregnant women referral to substance abuse treatment based upon the findings of screening. Continuing education units based upon this curriculum are available for nurses, substance abuse counselors, and social workers. This curriculum has been provided to the Great Basin Primary Care Association for training of clinical staff at its member clinics via the Internet, and training based upon this curriculum is being provided to Nevada Medicaid case managers providing services to Medicaid-eligible perinatal women.

3. Develop with the University of Nevada School of Medicine guidelines for identification of pregnant women at risk of consuming alcoholic beverages during pregnancy and for identification of children with FAS (NRS 442.390).

The FAS Subcommittee has determined that the T-ACE is the most appropriate screening instrument to identify pregnant women at risk of drinking during pregnancy. Training in the use of the T-ACE is provided in the curriculum described above.

The T-ACE is a brief screening protocol comprised of four questions:

1. How many drinks does it take for you to feel high? (**T**olerance)
2. Have people **A**nnoyed you by criticizing your drinking?
3. Have you ever felt you ought to **C**ut down on your drinking?
4. Have you ever had a drink in the morning (an **E**ye-opener) to steady your nerves or get rid of a hangover?

Screening guidelines to identify children with FAS have not yet been developed. The FAS Subcommittee has addressed identification of children with FAS in its report to the MCHAB on the best means of measuring the frequency of FAS in Nevada. Such identification should be based upon FASSnet criteria for both a "confirmed FAS phenotype" and for a "probable FAS phenotype", and head circumference may be an appropriate means of screening children for these criteria. However, the Subcommittee has not firmly established the best means of conducting such screening, and should do so during 2002.

4. Develop training materials for school personnel to assist them in identifying and providing referrals for children with FAS (NRS 442.385).

As noted above, the Subcommittee has not yet firmly established guidelines for screening of children for FAS but should do so during 2002. In addition, the Subcommittee did not have formal liaison with the Department of Education during 2001. Formal liaison now has been established by the Superintendent of Education appointing a proxy to the Subcommittee. Accordingly, training materials for school personnel should be developed during 2002.

5. Develop and implement guidelines for prevention of consumption of alcoholic beverages by pregnant women, with the goal of increased use of treatment services by substance-abusing childbearing women (NRS 442.380).

While the Subcommittee has discussed these issues, it has not developed formal guidelines for preventing alcohol consumption by pregnant women and for their increased use of substance abuse treatment services. Such guidelines should be developed during 2002.

The five elements listed above include primary (e.g. public education regarding the hazards of drinking during pregnancy), secondary (e.g. treatment of substance-abusing pregnant women), and tertiary (e.g. referral of children with FAS for services) prevention of FAS. The most effective means of preventing FAS in Nevada is to complete development of these elements of FAS-prevention required by NRS 442.350 *et seq*.

In the course of doing so, three central facts about FAS must be kept in mind. First, prevention of FAS will require prevention of unintended pregnancies since approximately half of all pregnancies are unintended, with the result that alcohol-related damage to the fetus may have already occurred before a woman knows she is pregnant. Second, while alcohol produces some of its most severe damage during the first weeks of pregnancy, further damage can be prevented and positive birth outcome made more likely if the woman stops drinking at any point during pregnancy. And third, in addition to public education and the other elements of a FAS-prevention program required by statute, existing activities must be coordinated and integrated with FAS-prevention efforts if these efforts are to be effective. These existing activities include:

- Substance abuse primary prevention programs

  The Bureau of Alcohol and Drug Abuse (BADA) provides funding to organizations providing primary prevention of substance abuse, utilizing State and Federal funds. School-based primary prevention programs have been demonstrated to successfully delay or prevent the onset of alcohol use. A recent study by the Mayo Clinic and the Centers for Disease Control and Prevention (CDC) reached the conclusion that such programs are crucial to preventing drinking and smoking among young pregnant women.

- Substance abuse treatment for alcohol-abusing women of childbearing years and alcohol-abusing pregnant women in particular.

  Increased treatment for alcohol-abusing women of childbearing years can reduce FAS in Nevada, and increased treatment for pregnant alcohol-abusing women can serve as an effective early intervention even if it is too late to prevent the fetus from suffering any ill effects from alcohol exposure.

  BADA administers State and Federal funding to treatment programs serving these populations, making affordable treatment available to all Nevadans. It is a condition of receipt of Federal Substance Abuse Prevention and Treatment (SAPT) Block Grant funds that treatment programs receiving these funds do not deny admission to pregnant women and provide them admission priority. Also as a condition of this funding, the State is required to publicize the availability of treatment for pregnant women and the admission priority they receive.

  In addition, a portion of the SAPT Block Grant is set aside for treatment of pregnant women and women with dependent children. Programs receiving this set aside funding are subject to a number of additional requirements addressing the specific treatment needs of this population (e.g. treating the family as a unit) and potential barriers to its treatment (e.g. childcare). At present there are two such programs in Nevada, the Healthy Families Project in Clark County and Step 2 in Washoe County, and both invariably have waiting lists. The current BADA application for SAPT funding states intent to expand these services into the balance of the state.

- Prevention of unplanned pregnancy

  Birth control is a potentially contentious issue, but cannot be ignored in an effective FAS-prevention campaign. Women of childbearing years are commonly advised not to drink

alcoholic beverages during pregnancy or when planning on becoming pregnant, but the utility of this advice is greatly diluted by half of all pregnancies being unplanned. While most women quit drinking when they find they are pregnant, with an unplanned pregnancy much of the damage of prenatal alcohol exposure may have already occurred when the woman finds that she is pregnant.

The public health system makes birth control generally available to all Nevadans regardless of economic status, although this is not greatly publicized. In addition, the Bureau of Family Health Services implements a school-based abstinence-only teen pregnancy prevention program, while Community Action Teams address teen pregnancy at the local level and with local control over whether teen pregnancy prevention shall be abstinence-based, adopt a harm-reduction strategy, or both. As with harm-reduction approaches to substance abuse, harm reduction approaches to teen pregnancy can be controversial since efforts to reduce harm consequent to proscribed behavior may be construed as permission or encouragement to engage in it.

- Statutes and regulations

  Appropriate statutes and regulations can enhance FAS-prevention efforts. For example, during the 2001 Nevada legislative session SB 277 nearly passed, which would have required posting of FAS-warning signs at food establishments engaged in retail sales of alcoholic beverages.

  Statutes and regulations can also impede FAS-prevention efforts. During the 2001 Nevada legislative session SB 212 and AB 206 would have eliminated the current requirement that health insurance policies and health maintenance organizations provide coverage for substance abuse treatment and for birth control services. This legislation did not pass out of committee.

  Demand-reduction through statutory and regulatory action to raise the price of drugs is a common prevention tactic. With illicit drugs, this tactic takes the form of interdiction, the effectiveness of which is commonly assessed by its effect on street prices. With tobacco and alcohol, this tactic takes the form of increased taxation. Excise taxes on alcoholic beverages in Nevada have not been raised since 1983. In 1995 a "Nickel a drink" initiative was introduced under Assembly Bill 90, which did not pass. This bill would have raised State excise tax on alcoholic beverages, with the funds generated targeted for substance abuse prevention activities.

Recommendations

- **State taxes on alcoholic beverages should be increased, both as a means of reducing alcohol abuse and of generating State funds.**

Taxes imposed on alcoholic beverages by the State of Nevada are well below the national average and have not been raised since 1983. There is evidence that increasing the price of alcoholic beverages through taxes reduces alcoholic beverage consumption by pregnant women, and that increases in the price of alcoholic beverages is especially likely to reduce alcoholic beverage consumption by youth and the poor. Note that statute requires State taxes on beverages with more than 22% alcohol to be used for substance abuse services.

- **Children should be screened for Fetal Alcohol Syndrome (FAS), with those at risk of having the syndrome (e.g. those with small head circumferences) being referred to a qualified professional trained in diagnosis of FAS.**

This could serve not only as a means of measuring the frequency of FAS, but also serves the function of secondary prevention – i.e. early identification and intervention – of the disorder. Early diagnosis of FAS has been determined to be a key protective factor in prevention of secondary disabilities such as inappropriate sexual behavior and substance abuse.

- **State law should require retailers of alcoholic beverages to prominently post clearly legible signs warning of the hazards of drinking alcoholic beverages during pregnancy.**

Federal law already requires that the labels of alcoholic beverages have the Surgeon General's warning that drinking alcoholic beverages during pregnancy can cause birth defects. This warning is small, easily ignored, and absent when alcohol is bought by the glass. State law requiring retailers to visibly post a legible warning sign consistent with the Surgeon General's warning nearly passed during the 2001 Legislative Session and should be re-introduced during the 2003 session.

- **Appropriate services for children and adults with FAS should be provided to ensure that people with FAS live full lives in their communities and to reduce their risk of themselves having children with FAS.**

Much of the social and personal cost of FAS is due to secondary disabilities, especially those associated with central nervous system damage. These secondary disabilities include school difficulties, difficulties with employment and independent living, difficulties with the criminal justice system, and substance abuse. Persons with FAS are far more likely than others to themselves have children with FAS. The Centers for Disease Control and Prevention has identified early identification of FAS and subsequent provision of appropriate services to be a factor, which tends to protect a person with FAS from these secondary disabilities.

- **Counties in Nevada should adopt ordinances requiring that persons serving alcoholic beverages by the glass be trained in the dangers of excessive alcohol consumption and in its physiological effects, including its effects on the fetus.**

Clark County ordinance requires training of persons serving alcoholic beverages by the glass to ensure that such serving is done responsibly. No other county in Nevada has such a requirement. Requirements similar to the Clark County ordinance should be adopted by other counties in Nevada, requiring that training curriculum include the dangers of drinking alcoholic beverages during pregnancy, while adapting the ordinance to address local concerns.

- **Efforts should be made to reduce the frequency of unintended pregnancy in Nevada. FAS prevention-education should be integrated with efforts to prevent teen pregnancy in Nevada. Substance-abusing women of childbearing years especially should be targeted for access to family-planning services. Sexually-active substance-abusing**

women of childbearing years who are not amenable to substance abuse treatment should be encouraged to practice long-term birth control or given the option of voluntary sterilization.

Both in Nevada and nationwide, half of all pregnancies are unintentional. This means that a woman may have already harmed her fetus through alcohol abuse before she even knows that she is pregnant. Reduction in unintended pregnancies would reduce the frequency of FAS and other alcohol-related birth injuries. Efforts to reduce teen pregnancy in Nevada should include within their curriculum information regarding the hazards of drinking during pregnancy since teen pregnancy is particularly likely to be associated with substance abuse.

Sexually active women of childbearing years who use alcohol or other drugs should be encouraged to practice family planning. Substance abusing women often are noncompliant with short-term birth control regimens such as condoms or birth control pills. While treatment should be the first option of a substance-abusing woman, not all are amenable to treatment. Those who are sexually active and who do not attain sobriety should practice long-term birth control such as d-Provera or Norplant. Voluntary sterilization can be appropriate for some so long as consent is truly informed and there is complete absence of coercion.

Report of the Fetal Alcohol Syndrome Subcommittee to the Maternal and Child Health Advisory Board on 5/14/02:
Best Means of Measuring the Frequency of FAS in Nevada

ABSTRACT: The letter of SB 197, passed into law during the 1999 Nevada legislative session and now codified as NRS 442.350 *et seq*, requires that the Fetal Alcohol Syndrome (FAS) subcommittee of the Maternal and Child Health Advisory Board identify the best means of measuring the "incidence" of FAS in Nevada. The law uses a definition of the syndrome that includes Fetal Alcohol Effect (FAE) within the syndrome.

For technical reasons the frequency of FAS in Nevada would best be measured as its prevalence instead of its incidence. Also for technical reasons, the definition of FAS used for this purpose should be the Center for Disease Control and Prevention's FASSnet definitions for confirmed and probable FAS phenotypes instead of the statutory definition.

Passive means of FAS-surveillance (e.g. birth-certificate data, birth defects registries) are financially attractive, but typically produce inaccurately low findings. Active means (e.g. outreach and screening) can be much more accurate, but can be prohibitively expensive. The best means of measuring the prevalence of FAS in Nevada would be to achieve a balance between accuracy and costs through stratified active surveillance. For example, FAS-screening of grade school children to refer those below the 10^{th} percentile for head circumference for diagnostic assessment could provide prevalence data of acceptable accuracy at far less cost than universal screening. While stratification can reduce the costs of active surveillance, any form of active surveillance will require adequate new funding.

At present passive FAS surveillance data is becoming available through the Birth Defects Registry. This data must be interpreted as the product of passive FAS-surveillance and thus likely to underestimate the number of cases of FAS. However, Birth Defects Registry data on FAS could potentially provide incidence data and is the best means of surveillance currently being implemented.

Five recommendations appear at the end of the report.

NRS 442..375 assigns to the Fetal Alcohol Syndrome (FAS) Subcommittee of the Maternal and Child Health Advisory Board responsibility for determining the best means of "collecting information relating to the incidence of FAS in this state." Statute requires this finding to be reported to the Maternal and Child Health Advisory Board. Critical to this determination is the definition of FAS.

Definition of FAS

Fetal Alcohol Syndrome was first described in France in 1968, and the term was coined by American researchers in 1973. The classic definition of FAS is that it refers to a cluster comprised of each of the following in association with a history of prenatal alcohol exposure:

1. Characteristic facial deformities;
2. Low birth weight; and
3. Central Nervous System (CNS) damage.

The term "Fetal Alcohol Effect" (FAE) was coined to indicate the need for follow-up when one or more, but not all three, elements of FAS are present. The statutory definition (NRS 442.003) of FAS collapses the distinction between FAS and FAE: "Fetal alcohol syndrome includes fetal alcohol effect."

FAE was intended to indicate only the need for further assessment and follow-up, not as a diagnostic term. This has not prevented the terms use as a diagnostic term. Since much precision of meaning of the term has been lost, in most professional contexts the term "FAE" has fallen into disuse.

In professional contexts the term has largely been replaced by the more narrowly-defined terms "Alcohol-Related Birth Defects" and "Alcohol-Related Neurological Disorder". In addition, the Institute of Medicine considers characteristic facial deformities in conjunction with one, but not both, of the other signs of FAS to constitute a subcategory of FAS called Partial FAS if there is confirmation of prenatal maternal alcohol abuse.

The issue of whether a history of prenatal maternal alcohol abuse is confirmed further diminishes the epidemiological validity of FAE. For example, while it may be rare for facial malformations, low birth weight, and CNS damage to all co-occur in the absence of prenatal maternal alcohol abuse, low birth weight alone can have any number of causes. This difficulty is greatly compounded by the tendency of alcohol abusers to deny alcohol abuse and the common absence of other means of confirming alcohol exposure during pregnancy.

Even were it possible to diagnose FAE with an acceptable degree of reliability, including FAE within the definition of FAS for epidemiological purposes would result in Nevada having an idiosyncratic definition of FAS. This would make comparison of Nevada data with national data or data from other states impossible: Since it is generally estimated that there are eight cases of FAE for each case of FAS, a definition that includes FAE within FAS would likely produce an eightfold inflation of Nevada data.

The Centers for Disease Control and Prevention (CDC) is conducting pilot FAS-surveillance projects in five states. For this project the CDC created FASSnet criteria for FAS, which currently is the best definition of the syndrome to use for epidemiological purposes. These criteria objectify the classic signs of FAS and do not include FAE within the definition of FAS.

FASSNet Case Definition

The FASSNet case definition for fetal alcohol syndrome (FAS) includes three components:

1. **Face**: Abnormal facial features consistent with FAS or two or more of the following: short palpebral fissures, abnormal philtrum, thin upper lip.
2. **CNS**: At least one structural (birth or postnatal head circumference at or below the 10th percentile) or functional (e.g., mental retardation, developmental delay) central nervous system anomaly.
3. **Growth**: Intrauterine or postnatal growth delay (e.g., weight for age at or below the 10th percentile, length corrected for gestational age at or below the 10th percentile).

Children who meet all three components of the case definition are considered to have a confirmed FAS phenotype.

Children who meet the face component and either the CNS or the growth component are considered to have a probable FAS phenotype.

Confirmed and probable cases are further categorized as to whether documentation exists in the child's and/or mother's record of some level of maternal alcohol use during the pregnancy.

At present the best definition of FAS for determining the frequency of FAS in Nevada is FASSnet criteria.

Incidence versus Prevalence

While statute calls for identification of the best means of measuring the incidence of FAS, this is exceedingly problematic. Measurement instead of its prevalence is much more feasible. "Incidence" refers to the number of new cases during a given time frame. The incidence of FAS most commonly reported as the number of children born with the syndrome per 1000 live births during a year.

An inherent difficulty with measuring the incidence of FAS is that diagnosis at birth is exceptionally difficult except in the most severe cases. As the child matures the signs of the syndrome become increasingly evident, with diagnosis most easily conducted from age 6 to the onset of puberty. With the onset of puberty the physical signs of FAS (small stature, characteristic facial malformations) often become less evident over time. The Nevada Birth Defects Registry ameliorates the difficulties of early diagnosis of FAS by providing for surveillance until the child's sixth birthday.

"Prevalence", on the other hand, refers to the number of cases in the population at a given time and is not as subject to difficulties created by ease of diagnosis varying with the age of the child. The CDC FAS-surveillance pilot projects seek to assess the prevalence of the disorder.

FAS Surveillance

The Institute of Medicine (IOM) distinguishes between two general forms of FAS surveillance: Active versus passive. Passive forms rely upon reporting of cases of FAS or upon review of medical records. Active forms utilize outreach and screening. The IOM notes that while passive surveillance generally is very inexpensive, it generally produces excessively low estimates of the frequency of FAS. Active surveillance is far more accurate, but can be prohibitively expensive.

Nevada currently has passive FAS surveillance in the form of birth-certificate reporting and a Birth Defects Registry. The IOM cites both birth certificate data and birth defects registries as examples of mechanisms that yield inaccurate estimates of the frequency of FAS. Nevada's data are no exception: Birth certificate information indicates only one or two cases of FAS per year in Nevada, and the birth defects registry has identified but one probable case of FAS.

The difficulties of passive surveillance are exacerbated by difficulties inherent to the FAS as a diagnostic category. FAS certainly is useful as an epidemiological category, indicating severe disability caused by prenatal alcohol exposure. But the primary clinical purpose of a diagnosis generally is not to generate epidemiological data, but instead to indicate treatment of choice and prognosis for the patient. A diagnosis of FAS does a relatively poor job of indicating treatment of choice and prognosis due to the broad range of signs associated with the disorder. For example, many, but not all, children with FAS suffer from mental retardation. While a diagnosis of mental retardation gives some indication of treatment of choice and prognosis, a diagnosis of FAS does not because the child may or may not suffer from mental retardation. Early diagnosis of FAS has, however, been found to be a protective factor for secondary disabilities due to FAS, i.e. disabilities such as difficulties with the criminal-justice system developed secondary to CNS damage from FAS.

Clinicians remain more likely to diagnose the subsidiary disorders (such as mental retardation) than FAS. For this reason even making FAS a reportable condition (such as many communicable diseases) would be unlikely to produce accurate information regarding the frequency of the syndrome in the community.

Enhancing and encouraging clinician diagnosis of FAS is the focus of the CDC's FAS surveillance pilot projects. These projects, conducted in Alaska, Arizona, Colorado, New York, and Wisconsin, couple passive FAS surveillance with training of healthcare professionals to encourage their diagnosing of FAS. In Wisconsin the project has a limited active surveillance component comprised of screening conducted by a nurse or a dysmorphologist. The core of surveillance is review of medical records, much like that currently conducted in Nevada for its Birth Defects Registry.

While each of these pilot projects have been in operation for at least two years, none has yet to report findings with regard to prevalence of the syndrome. While enhanced by training of healthcare professionals, it has not yet been determined whether this will overcome the tendency of passive measures of FAS to produce low estimates. For example, prior to initiation of the pilot project Arizona, relying on essentially the same data sources as its pilot project, had obtained incidence rates ranging from 0.13 to 0.17 cases per 1000 live births. These are very low estimates

given that the CDC cites 1 to 3 cases per 1000 live births as the usual range of incidence estimates. The Arizona data reflects the tendency of passive means of FAS surveillance to provide very low estimates of its frequency.

The Arizona data also shows one of the benefits of birth defects registries. They can provide incidence data more useful than prevalence data in determining the effects of prevention efforts, especially in states like Nevada with a transient population. For an exaggerated example, even were FAS prevented in its entirety in Nevada there still would be new cases of FAS among persons moving to Nevada from other states. Prevalence data would not show that birth of children with FAS had been eliminated in Nevada. For this reason, incidence data available through the Birth Defects Registry should continue to be collected.

Passive means of FAS surveillance generally are attractively inexpensive, but also generally provide inaccurate data. Active means of surveillance can give accurate estimates but can be prohibitively expensive. For example, valid estimates of the frequency of FAS in Nevada could be obtained by having each child from birth to puberty annually examined by a physician trained in FAS diagnostics, but the cost of such a surveillance system would be prohibitive.

Costs of active surveillance can be contained to a great extent by stratified surveillance – i.e. providing outreach and screening only to a targeted subpopulation. For example, head circumference has been found to be a good predictor of FAS, and is very easily measured. Referring only children below the 10^{th} percentile for head circumference for a FAS diagnostic workup would reduce the frequency of such referrals by 90%.

A further potential criterion for stratification is age: FAS is generally considered to be most readily identifiable from 6 or 7 years of age to the onset of puberty. Screening only grade school children for small head circumference could attain a balance between surveillance costs and accuracy. Additionally, such a system could also serve as the foundation for early identification and referral of children with FAS.

While such a system would be more accurate than a passive system, and more affordable than universal screening, it must be noted that any active FAS surveillance system will have significant financial costs. In the absence of additional funding, only passive means of surveillance remain available. Passive means of FAS surveillance generally are not accurate enough to guide public policy or assess the results of prevention efforts.

Recommendations

- **Determination of the frequency of FAS in Nevada should be based upon FASSnet criteria for both a "confirmed FAS phenotype" and for a "probable FAS phenotype".**

Clinical definitions of FAS vary and have changed over time, while the statutory definition of FAS includes Fetal Alcohol Effect, which could result in misinterpretation of Nevada data. The CDC has developed FASSnet criteria for "confirmed" and "probable" FAS phenotypes specifically for FAS epidemiology. The FASSNet criteria for fetal alcohol syndrome (FAS) includes three components:

1. **Face**: Abnormal facial features consistent with FAS or two or more of the following: short palpebral fissures, abnormal philtrum, thin upper lip.
2. **CNS**: At least one structural (birth or postnatal head circumference at or below the 10th percentile) or functional (e.g., mental retardation, developmental delay) central nervous system anomaly.
3. **Growth**: Intrauterine or postnatal growth delay (e.g., weight for age at or below the 10th percentile, length corrected for gestational age at or below the 10th percentile).

Children who meet all three components of the case definition are considered to have a confirmed FAS phenotype. Children who meet the face component and either the CNS or the growth component are considered to have a probable FAS phenotype.

- **Determination of the frequency of FAS in Nevada should be based upon the syndrome's prevalence.**

  While statute calls for the FAS Subcommittee to identify the best means of measuring the syndrome's incidence (e.g. number of cases per year per 1000 live births), due to difficulties with early diagnosis a more accurate measure is likely to be its prevalence (e.g. number of cases per 1000 people in the population).

- **Surveillance to determine the prevalence of FAS in Nevada should address the need for both accuracy and cost-effectiveness by utilizing a stratified means of active surveillance, such as screening to refer for diagnostic evaluation those grammar school children below the 10th percentile for head circumference.**

  Passive surveillance (e.g. Birth Defects Registry) tends to be inexpensive, but also produce inaccurately low findings. Active surveillance (e.g. outreach and screening) can be accurate, but can also be prohibitively expensive. Stratified active surveillance screening a portion of children for the syndrome could be both affordable and accurate.

- **Data should continue to be gathered through the Birth Defects Registry as a potential means of measuring the incidence of FAS, but this and other passive means of FAS surveillance must be interpreted as under-reporting the frequency of FAS.**

  While the Birth Defects Registry is likely to produce low estimates of the incidence of FAS in Nevada due to difficulties with early diagnosis of FAS and with passive surveillance systems, data should continue to be gathered through it. This Registry has the potential of yielding incidence data, which in some respects is superior to prevalence data, and at present it is the best FAS-surveillance system in Nevada. Its data, however, must be interpreted appropriately.

- **To ensure that Nevada data is comparable with data from other sources, data for cases of confirmed FAS phenotype and for cases of probable FAS phenotype should be maintained separately.**

Some epidemiological studies may be based upon the FASSnet criteria for only a "confirmed" FAS phenotype, while others may be based upon both that criteria and that for a "probable" FAS phenotype as has been recommended for Nevada. Data for the two phenotypes should be maintained separately so that it may be compared with diverse sources.

APPENDIX E

Report of the Fetal Alcohol Syndrome Subcommittee to the Maternal and Child Health Advisory Board on 12/2/02: Guidelines for Prevention of Consumption of Alcoholic Beverages during Pregnancy

Since 1989 the Surgeon General has warned that pregnant women and women who intend to become pregnant should not consume alcoholic beverages because of the risk of birth defects. Because so many pregnancies are not planned, this caution should be extended to sexually active women of childbearing years who are not practicing birth control. Half of all pregnancies are unintended, and alcohol can do some of its most severe damage during the first weeks of pregnancy when a woman may not know she is pregnant. Women who are or may become pregnant should not drink alcoholic beverages because of the risk of alcohol-related birth injuries, including Fetal Alcohol Syndrome (FAS).

Under Nevada law abuse of alcohol or other drugs during pregnancy is not considered child abuse (Sheriff, Washoe County v. Encoe, 1992). However, if the child is born with FAS or congenital addiction, the child can be taken into protective custody (NRS 442.330). This means that a pregnant substance-abusing woman can obtain substance-abuse treatment and prenatal care without fear of intervention for child abuse. However, this also means that if she does not obtain help, and her child is born with FAS or with congenital addiction, the child then can be taken away from her.

The hazards of drinking alcoholic beverages should not be minimized, but neither should they be exaggerated. Exaggeration of the hazards of drinking alcoholic beverages during pregnancy may lead an alcohol-abusing pregnant woman to avoid rather than obtain prenatal care and substance-abuse treatment, thinking that damage to the fetus is inevitable. For the same reason, exaggeration of the hazards of drinking alcoholic beverages during pregnancy could lead to unnecessary abortion. While no safe level of alcohol consumption during pregnancy has been established, neither has it been established that an occasional drink will harm the fetus. Fetal damage is usually associated with pathological patterns of alcohol consumption, i.e. binge drinking, alcohol abuse, and alcohol dependence. It also has been found that termination of even pathological levels of alcohol consumption at any time during pregnancy is likely to improve birth outcome.

While there is no evidence that an occasional drink is harmful to the fetus, it should also be recognized that negative evidence failing to find harm is much weaker than positive evidence of safety. For example, the Food and Drug Administration utilizes a 4-level classification system for the effects of drugs upon the fetus. Category “A” is comprised of those drugs that controlled human studies have found to be safe. Category “X” is comprised of those drugs that have been found to have a harmful effect upon the fetus and for which the risk of fetal injury is not offset by potential benefits. Alcohol is a Category “X” drug.

Sexually active women of childbearing years who drink alcoholic beverages should practice birth control to avoid unintended pregnancy and risk of fetal damage during the early stages of pregnancy. Women with abusive or dependent patterns of alcohol use often have difficulties maintaining compliance with short-term methods of birth control such as condoms or birth-control pills.

Accordingly, sexually active women of childbearing years who continue to abuse alcohol should obtain long-term birth control such as d-Provera, Norplant, or an Intrauterine Device (IUD). Voluntary sterilization of such women is a contentious issue, with some considering sterilization to be too important and too permanent a decision to consider in the absence of long-term sobriety. Substance-abusing women of childbearing years, whether practicing birth control or not, certainly should consider obtaining treatment.

If a woman who is or may become pregnant finds herself unable to abstain from alcohol, she should obtain an assessment to determine whether she is in need of treatment for alcohol abuse or dependence. The Bureau of Alcohol and Drug Abuse provides funding to programs that make both assessment and treatment available with sliding scales of affordable fees. If a person is unable to pay at the time of receiving services, these programs will not deny services, but instead will establish a payment plan. Programs funded by the Bureau of Alcohol and Drug Abuse will not deny admission to a woman on the grounds that she is pregnant, and in fact will give her priority for admission. Some of these programs provide services such as childcare which are specific to the needs of pregnant women and women with dependent children.

Report of the Perinatal Substance Abuse Prevention Subcommittee to the Maternal and Child Health Advisory Board:
Tobacco Control

The health problems associated with tobacco use are well documented. The primary danger of tobacco use during pregnancy is low birth weight. Low birth weight in turn is associated with a number of disorders. Tobacco use during pregnancy is also a risk factor for miscarriage and premature labor.

There are two primary mechanisms for prevention of perinatal tobacco use. The first is prevention or delay of tobacco use: Nicotine addiction seldom occurs among those who do not use tobacco prior to 18 years of age. The second is smoking-cessation services for those who do smoke tobacco, especially to pregnant women who smoke tobacco.

A key to prevention of under-age smoking is supply-reduction – i.e. prevention of sales of tobacco products to children. Nevada's enforcement of its prohibition against tobacco sales to minors has improved greatly over the past several years commencing with delegation of enforcement authority to the Attorney General's Office in 1995. Prior to that time, Nevada's prohibition against tobacco sales to minors had been largely unenforced.

The Attorney General's Office has subsequently secured funding for enforcement through compliance checks. Compliance checks are conducted on a random and unannounced basis, and consist of an under-age teenager attempting to purchase tobacco. If the retailer sells to the minor, a citation is generally issued; if the sale is refused, the retailer is thanked for having done so.

A survey of randomly-selected tobacco retailers conducted prior to transfer of enforcement authority to the Attorney General's Office found that 64% of tobacco retailers sold tobacco to a minor. Tobacco retailers currently are subject to two compliance checks a year, and the "buy-rate" has fallen to 16.3%.

If a woman does take up smoking, pregnancy provides an excellent window of opportunity for stopping. Because the hazards that tobacco poses for the pregnancy are well known, a woman who smokes tobacco usually is motivated to quit when she becomes pregnant. The Nevada Section of the American College of Obstetricians and Gynecologists has formed the Providers' Partnership Project on Smoking among Women, which includes the Nevada Health Division as a partner. This partnership is disseminating to obstetricians, gynecologists, and to the physicians' staff in Nevada a smoking-cessation protocol which includes referral to the Nevada Tobacco User's Helpline for a year of support and follow-up. The Helpline is made available through the University of Nevada School of Medicine.

Associated with perinatal tobacco use is exposure of both pregnant women and children to environmental tobacco smoke. The health risks of environmental tobacco smoke are also well-documented. Nevada law currently prohibits smoking – and thus exposure to environmental tobacco smoke – in any:
"(a) Public elevator.
(b) Public building.

(c) Public waiting room, lobby or hallway of any:
(1) Medical facility or facility for the dependent as defined in chapter 449 of NRS; or
(2) Office of any chiropractor, dentist, physical therapist, physician, podiatric physician, psychologist, optician, optometrist or doctor of Oriental medicine.
(d) Hotel or motel when so designated by the operator thereof.
(e) Public area of a store principally devoted to the sale of food for human consumption off the premises.
(f) Child care facility [defined as one licensed to provide care to 13 or more children].
(g) Bus used by the general public, other than a chartered bus, or in any maintenance facility or office associated with a bus system operated by any regional transportation commission.
(h) School bus."

Further provisions of the law allow the owner of a public building to establish designated smoking areas, and allow grocery stores to permit smoking in areas leased by gaming operators. This law does not provide adequate controls over environmental tobacco smoke, with only two of the prohibited areas (day care centers licensed for 13 or more children, and school buses) being areas likely to be frequented by children.

A further concern related to childhood exposure to environmental tobacco smoke is observational learning by children. A large body of research has found that children have a great tendency to adopt behavior they observe. When children are exposed to environmental tobacco smoke, they typically are observing adults smoking tobacco.

State law (NRS 202.249) prohibits local governmental agencies from adopting more stringent controls over tobacco. This State pre-emption of local control over tobacco has been criticized on the grounds of preventing effective tobacco control, and defended on the grounds that State pre-emption prevents tobacco control in Nevada from being comprised of a confusing patchwork of widely varying local ordinances. Were State law to provide for adequate tobacco control, the issue of State pre-emption would become largely irrelevant.

Recommendations

- **Nevada law prohibiting tobacco sales to minors should be consistently enforced.**

  Enforcement of Nevada's law prohibiting tobacco sales to minors has been effective, but is contingent upon continued funding of enforcement by the Attorney General's office. This funding should be continued. Supply-reduction efforts to reduce under-age tobacco smoking can significantly reduce the number of women of childbearing years and pregnant women who smoke tobacco.

- **Smoking in areas which will expose children to secondhand smoke should be prohibited.**

  The Environmental Protection Agency states that, "Secondhand smoke affects everyone, but children are especially vulnerable because they are still growing and developing." The American Academy of Pediatrics has found that, "Results of epidemiologic studies provide

strong evidence that exposure of children to environmental tobacco smoke is associated with increased rates of lower respiratory illness and increased rates of middle ear effusion, asthma, and sudden death syndrome. Exposure during childhood may also be associated with development of cancer during adulthood."

However, with the exception of a prohibition against smoking in school busses and smoking in child care centers licensed to provide care to 13 or more children, Nevada law does not explicitly address exposure of children to environmental tobacco smoke. In addition, local governmental agencies are prohibited from adopting more stringent controls over where tobacco may be smoked. State law needs to provide children with greater protection from exposure to environmental tobacco smoke.

- **Smoking cessation programs should be made available to women of childbearing age and especially to pregnant women.**

The Nevada Section of the American College of Obstetricians and Gynecologists has established the Providers' Partnership Project on Smoking among Women. One of the partners in this organization is the Nevada Health Division. The Partnership is disseminating smoking-cessation protocols for pregnant women to obstetricians, gynecologists, and their staff. These protocols include provisions for referral to the Nevada Tobacco Users' Helpline, which in turn provides the woman with support and follow-up for one year. The Nevada Tobacco Users' Helpline is a service of the University of Nevada School of Medicine. The State of Nevada should continue its partnership in this project to make smoking cessation services available to pregnant women.